

*This paper describes a program for the evaluation of retarded children in the state of Washington. An analysis was made of 148 cases to see how well community resources were employed in carrying out the recommendations made for these children. The authors discuss some of the factors involved in success or failure.*

## **EFFECTIVENESS OF COMMUNITY RESOURCES IN HELPING MENTALLY RETARDED CHILDREN**

*Robert W. Deisher, M.D., and R. S. Justice, M.S.W.*

**M**ENTAL RETARDATION has received increasing attention over the past few years. Stimulated by organized parent groups and the availability of federal funds for use in this field many states have begun, or are in the process of beginning, projects for retarded children. The state of Washington has had an operating program for mentally retarded children since 1955. This program is jointly sponsored by the Washington State Department of Health and the University of Washington School of Medicine.

In the beginning the program was limited to a diagnostic center at the University of Washington School of Medicine. This center, the Clinic for Child Study, provides complete services to diagnose and evaluate retarded children. The clinic also provides an opportunity to teach community agencies and persons working with these children locally about the problems of retardation and how they can be handled. The staff of the diagnostic center includes a pediatrician, a public health nurse, social worker, psychologist, psychiatrist, speech and hearing therapist, neurologist, nutritionist, and dental hygienist. Laboratory facilities are available. In addition,

parent guidance, coordination of community resources, community education, and training of professional personnel both at the community and the university level are part of the clinic program. The clinic works with the health department at state and local levels, the various state departments, such as Institutions, Public Instruction, and Public Assistance, as well as local school districts, local parent groups, and physicians. It was planned initially that the area from which patients should come would be limited to one county, thereby limiting number of agencies, organizations, and individuals involved.

Training of community personnel has been a very important part of the program. Special sessions have been given in the local area for public health nurses, for workers in the Department of Public Welfare and for the ministerial association. Length of time for a training session has been from two to six hours and a total of 234 individuals have attended these sessions.

The Clinic for Child Study opened at the University of Washington, November 1, 1955. Patients were seen on a referral basis from one county selected for the pilot study initially and later

**Table 1—Source of Referral**

Private physician	62
Schools (includes social worker, psychologist, school nurses and teachers)	32
Public health nurse	22
Children's Hospital	9
Welfare Department	7
Child Guidance Clinic	6
Other University of Washington clinics	5
Courts	3
Ministers	1
State School for the Retarded	1
	—
	148

from a second. Referrals were made to the local health department and from there to the clinic. This was in order to establish the local health department as the coordinating agency and to do as much as possible in management and coordination at a local level. Referrals were accepted by the health department from physicians, welfare workers, public health nurses, school personnel, or other competent professional persons.

Table 1 is based on the first 148 cases seen in the clinic. It shows the largest number of referrals to have been made by private physicians, 62, or 41.8 per cent. Second highest number was from the school, 32, or 21.6 per cent. School referrals include referrals from school teacher, nurse, social worker, or psychologist. The third was from the public health nurse, 22, or 14.8 per cent. Occasional referrals were made by the Department of Public Welfare, the local child guidance clinic, the juvenile court, other University of Washington clinics, the state school for the retarded, and the Children's Hospital.

The age limits were set from birth to eight years as it was believed that relatively more might be accomplished with younger children. Eight was chosen

as the upper age limit so as to include children who might have been shown to be retarded only when faced with entrance into the public school.

Table 2 shows the age and sex of the first 148 patients referred to the clinic. Although the age of eight was set as the upper age limit for referral of children, a number of exceptions were made. These were made largely because it was felt that the case presented either an excellent opportunity for teaching or as was the situation in several instances the child was presenting a problem to the local community in which a number of people and agencies were involved and our evaluation would be particularly helpful from the standpoint of stimulating community interest and understanding of retardation. Although it is not shown in the table, the younger children were more likely to be referred by a physician, while those in the upper age

**Table 2—Age and Sex Distribution of Patients Seen in the Mental Retardation Clinic**

Age (Years) *	Male	Female	Total
1	4	5	9
2	5	2	7
3	9	3	12
4	21	8	29
5	12	9	21
6	15	2	17
7	12	8	20
8	8	7	15
9	5	3	8
10	1	2	3
11	2	0	2
12	0	3	3
13	1	1	2
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Total	95	53	148

\* One year=0-18 months, two years=19-30 months, three years=31-42 months, etc.

groups, particularly between five and eight, were referred by the schools or personnel connected with them. Referrals by public health nurses were scattered about equally through the entire age range.

The social worker on the clinic staff spent part-time in the local health department where a social history was obtained from the family. Whenever possible, he helped another person, such as a public health nurse who already knew the family, secure the necessary additional information. On occasion he has made a home visit himself. This information then is made available to the clinic before the patient's visit.

The first person to see the child when he comes to the clinic is the public health nurse. She has had experience in nursery school work and is able to function not only as a public health nurse but also as a person highly trained in observing preschool behavior. She obtains the height, weight, temperature of the child, and spends from 30 minutes to an hour with the child in an unstructured play situation. While the nurse is observing the child, the pediatrician talks to the parents. Then he examines the child. After this the child is seen and tested by the psychologist. Routinely, the patient is given appointments for the interviews with the clinic psychiatrist, nutritionist, dental hygienist, and the speech and hearing consultant. Appointments with other consultants are made when recommended by the pediatrician. Arrangements are also made for x-rays, electroencephalograms, and other laboratory work that may seem indicated.

After each member of the clinic team has had an opportunity to study a child a conference is held, at which all members of the staff discuss their findings and attempt to determine the cause of the child's retardation as well as to decide the most realistic future planning for the family and child. This confer-

ence provides excellent teaching for medical students, residents, student social workers, nurses, and other university students. To this conference professional persons from the community who know the child and are interested in the case are invited. They are usually the referring individual and several others representing local agencies. Each case presented has averaged two to three visitors from the local community, and their added information and interest concerning the child have been of considerable help in the conference. Attendance at the discussion has enabled the local people to participate in the planning for the child and to be most effective in carrying out a program at the local level. These conferences are thought to be valuable as a means of inservice training for the individual community members also.

Following the conference parents return to the clinic. At this time the pediatrician talks with them about the findings of the various members of the clinical team and the suggestions that have been made. Recommendations frequently involve contact with other social agencies in the community. Through the clinic social worker the parents are helped to get in touch with the recommended agencies which also receive pertinent information concerning the child and family. A complete summary report is sent back to the referring individual in the local community, with a copy to the local health department. When physicians are involved a letter or telephone call is made by the pediatrician. Community resources that have most frequently been recommended have been the public health nursing service, casework service, and special classes in the public schools.

We have been especially interested in evaluating these resources of the local community. Of particular interest has been their effective utilization by the patients. We wished to see if certain

**Table 3—Nature of Recommendations Made by the Clinic for Child Study and Efficiency of Implementation**

	Recommen- dations	Imple- mented
Public health nurse service	33	33
Special classes	24	22
Casework service	20	15
Nursery schools	15	11
Special medical care	14	13
Special parental help	13	7
Institutionalization	13	12
Speech therapy	9	6
Special dietary changes	9	8
Psychiatric therapy	8	2
Foster home	7	4
Dental care	4	4
	169	137

resources were more widely used than others and the reasons for the apparent lack of success with others. The records of the first 148 patients evaluated in the clinic were examined approximately one year after completion of the child's evaluation. A combination of the summary letter and the record of the parent conference was used to determine the specific recommendations made. Re-evaluation studies were obtained on approximately 60 patients. Personal and written communication with local workers were used to determine whether or not recommendations had been carried out in others. Table 3 shows that there was follow through in all cases referred for public health nursing visits and dental care. These were the only two categories in which there was 100 per cent follow through. Follow through here was not accomplished without a great deal of effort and cooperation on the part of both the clinic public health nurse and

the supervisor of public health nursing in the local health department and her staff. Certainly, the teaching about mental retardation received by the public health nurses early in the program contributed to their familiarity with the problems of mental retardation and their willingness to become involved in these cases. On each case referred to the public health nurse by the clinic a flow slip was sent to the local health department indicating the specific areas in which it was felt the family needed help from the nurse. In addition, the local health department had a complete copy of the case history to which the nurse could refer. Frequently the public health nurse had attended the case conference in which the help to be desired from a nursing visit was discussed. In a small per cent of the cases the public health nurse was already going into the home prior to evaluation. This, however, was not true in a large number of cases. Those cases where the public health nurse had initiated the referral were not usually being visited regularly by her at the time they were referred. Many of these were picked up in the well baby clinic of the health department, or cases were called to her attention by other persons who did not make the referral themselves.

Children referred for dental care were those who the dental hygienist felt were in particular need of restorative work. Several of the families had been aware of this but had been unable to find a dentist willing to work with a child whose management was difficult. Parents were helped to find dental facilities willing to accept such special problems. It should be added, while discussing dental care, that the dental health education given by the hygienist was very well received and much needed in a large number of cases. It was not possible, however, to adequately evaluate how well parents were following through on this, though those seen for reevalua-

tion seemed to be doing a better job than formerly.

The next category, designated special classes, also received follow-up in most cases. Children referred for this reason were those of preschool or school age where it was felt that the child would benefit from contact with other children, as well as from a training program appropriate to his abilities. Frequently there was a facility in the community of which the parent was aware but did not know how to contact, or the parent was somewhat unsure as to the child's readiness for this type of experience. Included within this classification are a number of children who were already in contact with the public school at the time of referral. In fact, some of these children were actually referred by the public school. They were, however, in most cases, in the regular kindergarten or elementary grades and presented a considerable problem to the school. The school was extremely grateful for the type of work-up available through the clinic and was receptive to any suggestions regarding the placement of the child.

There were 20 referrals for specific casework help. These referrals were made to personnel trained in casework service and included workers in the department of public assistance, school social workers, and others connected with agencies most able to give the type of help needed. It was sometimes necessary for the clinic social worker to spend considerable time himself with patients prior to their referral. Some were reluctant to admit the need for this type of help, while others were simply unaware of the existence of such help and needed only to know how they might get in touch with the agency's caseworker. In five cases referred for service there was no follow-up due almost entirely to the family's reluctance to accept referral for help of this kind. It is true that in some cases the agency did not particu-

larly extend itself to help the patient, but in no case could it be said that there was actual unwillingness on the agency's part. We were aware that this reluctance on the part of patients might exist and went to considerable effort to prepare them prior to referral. However, one-fourth were still unwilling to accept the referral. I am sure had it not been for the intensive efforts of the clinic's social worker a much higher number of failures would have resulted.

For the next category, nursery schools, the referral was somewhat less successful. Frequently this recommendation was made in order to give the child an opportunity to have other experiences than he was having at home and to free the mother for a short time from the constant burden of supervising the child. The referral could have been made considerably more often if there had been nursery schools within a reasonable distance of the family. Those where success was not possible were largely cases in which the nursery school was unwilling to admit a retarded child. Many expressed some hesitation when we suggested this, but the majority were willing to try to have a retarded child in their normal group. Some, however, despite effort on the part of the parent and the clinic social worker, were unable to accept this idea.

The next two categories, special medical care and special parental help, do not rightfully fall under the classification of community agencies. However, these recommendations were made often enough so that we felt their follow-through by the parents might be of some interest. Special medical treatment, which was recommended 14 times and satisfactorily accomplished in 13 instances, was a type of help quite acceptable to the parent. These were cases of children who needed minor surgery, such as tonsillectomy, glasses, hearing aid, or sometimes special medication. That special parental help for the child which

was recommended 13 times and only carried out successfully seven times probably needs some clarification. Here suggestions were made to the parent about providing specific kinds of help for the child which the parent might do within the home. However, this did involve a special effort on the part of the parent and a significant amount of time in as much as these had to fit into the daily program of the parent and child. To illustrate, a number of times a child who was having difficulty with speech was felt by the clinic speech consultant to be able to benefit from parental stimulation. Often a book called "Talking Time" was recommended to the parent as a guide. Another illustration might be a recommendation that the parent allow the child to have more freedom, for example, by being allowed to do what he wanted in a special room in the home set aside for this purpose, or as in one instance by fencing in a portion of the yard and thus allowing the child outside the house. All suggestions made were felt to be reasonable in terms of time and cost and were able to be carried out if the parent wanted to make the effort.

Recommendations for institutionalization were made 13 times in this group. These do not include a small number of cases who had already been placed on the institution waiting list prior to evaluation. It may seem somewhat surprising that this step was not recommended in a larger number of cases. However, because of the tremendous waiting list in our state institution and the unlikelihood of certain children being admitted in the foreseeable future, we did not want to build up false hopes in the minds of parents that their children would be able to get into the institution. A number of these children were quite severely retarded and yet the parents could not discuss the subject of institutionalization at the beginning of evaluation. Not only the social worker but the entire

clinic staff helped prepare the parent for the recommendation. Many were unwilling to consider it simply because of a lack of knowledge of what the institutional program offered. Frequently the clinic social worker arranged for the parents to meet with someone on the institutional staff or to visit the institution. This greatly facilitated the parents' willingness to consider this possibility, although in some cases a number of visits with the social worker were required to help the parents with their feelings regarding institutionalization.

Speech therapy refers to help with speech given by a person especially trained in this field. The recommendation was not made if it was felt there was no one available to the family or that it required an unreasonable effort on the family's part. In the majority of cases this was followed through. Those that were unsuccessful were largely due to the unwillingness of the parents to take the child to the place where such help was available.

The next category of change in dietary management was usually made on the basis of the clinic nutritionist's recommendations. This does not include simple suggestions and ideas that were given to the majority of patients interviewed by the nutritionist, but applies to those cases in which a major shift in dietary management was indicated. As can be seen parents were enabled to inaugurate this change with more facility than many of the other types.

The next category, that of referral for psychiatric therapy, is interesting in that it shows the least successful result. Most of these cases were children who on evaluation were not found to be retarded or only slightly so. Usually there was a large element of emotional disturbance. In some measure the lack of success was due to the parents' unwillingness to accept the fact that their child had an emotional problem. It is rather surprising that many of these parents ap-

parently preferred to believe that their child was basically mentally defective rather than that it was simply functioning at a defective level on the basis of emotional problems. These parents, despite careful interpretation and sometimes considerable casework in order to help them understand their child's condition, were unwilling to consider psychiatric therapy. However, it should be mentioned that there was also some reluctance on the part of psychiatric facilities to provide service to these children. Often the initial request for help was met with the statement that the facility already had a large number of children who needed service and that it was felt that the staff should not spend time with children who were retarded. Even when it was pointed out that these children were not actually retarded, this reluctance persisted. Several times parents endeavored to make contact with this facility but were discouraged from returning. It must be said, however, that this attitude did change somewhat over a period of time and at present cooperation from agencies of this type has greatly improved.

The authors are associated with the University of Washington School of Medicine, Seattle, Wash.

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Foster homes were recommended for seven retarded or emotionally disturbed children. These were cases where the child's management in the home was felt to be so detrimental that the only effective way of improving the situation would be to remove the child from his environment. These were cases in which it was felt that a foster home could meet the child's needs better than an institution. The main difficulty here has been the lack of foster homes willing to accept these children and not an unwillingness on the part of the parent to have the child removed from the home. Considerable effort was expended on each case to locate foster homes through a number of agencies but without success.

### **Summary**

A program for the evaluation of retarded children of Washington State has been outlined. The first 148 cases studied have been analyzed as to the effective utilization of local community resources. Some reasons for the success or failure of these recommendations have been discussed.

